Improving Support for Staff who are Carers

“I have been very grateful for the support provided by my managers and co-workers and the system’s flexibility including permanent part-time work and using FACS and PCL and LSL that has enabled me to remain in the work force”

Working + Caring = Double Shifts Every Day
For further copies of this document please contact either department listed above.
Jointly produced by Carers’ Program and Human Resource Department.
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Foreword

In the last two decades, increasing concern about the circumstance of many Carers has prompted governments and communities to act at local, state and national levels to make positive changes to better support Carers. Greater recognition of the important role Carers play in looking after relatives and friends who are ill, disabled or frail and ageing has been achieved in many areas.

One important development has been the completion of the “Improving Support for Staff Who Are Carers” Survey in the Sydney and South Western Sydney Local Health Districts. In looking at the results of the survey, it is gratifying to see the struggles of many Carers who juggle working and caring roles on a daily basis, have been recognised and acknowledged.

Given the recent proclamation of the NSW Carers (Recognition) Act 2010, the results of this survey have particular significance. The Act clearly articulates a role for Public Sector and human service Agencies in supporting employees who are Carers themselves, as well as meeting obligations to inform all employees about the needs of Carers. The survey succeeds in bringing the needs of working Carers to the forefront.

I commend Sydney and South Western Sydney Local Health Districts for seeing the part they can play in reducing this struggle between work and caring, by introducing flexible policies and practices that not only can support working Carers but other employees as well. The result will be a happier and more productive workforce and organisations that can better meet their goal of providing a high standard of health care to all citizens of New South Wales.

It is heartening that survey results show the majority of working Carers employed by Sydney and South Western Sydney Local Health Districts already feel supported by their management and employer. I acknowledge these pleasing results.

However, a significant proportion of respondents commented on difficulties in combining work and caring and suggested ways of better managing these concerns in the workplace. I urge Sydney and South Western Sydney Local Health Districts to note these comments and to take a leading role in supporting working Carers by acting on the recommendations of this report.
Focus

A “Working Carer” is defined as a person who is in paid employment and provides ongoing support to a family member or friend who has a disability, mental illness, chronic condition or who is frail aged. The Carer may work full time, part time, casually or be self-employed.

Working Carers Gateway

A “Caree” (care recipient) is the person the Carer looks after.

Self-defined
Map of South Western Sydney Local Health District
Special thanks to
Dr Sian Keane
Jan Heslep,
Mary Kang,
Michele Horgan
& Caitlin Wheelahan

for their assistance in completing this report.
Executive Summary

This report, *Improving Support for Staff who are Carers* summarises the results of a survey of staff who are Carers working for the Sydney Local Health District and South Western Sydney Local Health District. The survey provided opportunity for working Carers, many of whom are hidden to our organisations, to express concerns about their dual roles of working and caring. Respondents were also able to provide information about what would assist them to function in their role as part of the LHD workforce.

It provides recommendations about flexible workplace practices to support staff who are Carers; knowledge and resources to assist working Carers; and the education needs of managers and other staff in relation to Carers.

**Background**

Carers Program staff realised that little was known about staff of the former Area Health Service (AHS) who were working Carers and developed a project plan that included surveying staff to:

- Estimate how many staff identified themselves as a Carer;
- Identify staff concerns in combining workplace and caring responsibilities;
- Ascertain whether they felt supported by the organisation;
- Identify gaps Carers’ perceived in this support;
- Provide comment on how these gaps might be addressed.

The team also believed that this information would have value for workforce development programs and management of human resource. A partnership with the Workforce Planning and Development Unit was established to meet KPIs of the then SSWAHS Carers’ Action Plan.

**Working Carers in Sydney and South Western Sydney Local Health Districts**

- 329 working Carers completed the On Line survey.
- While 83% of respondents spoke English at home, 26% came from CALD backgrounds and 31 languages other than English were spoken, showing the cultural and linguistic diversity of LHD staff.
- Almost half of the Carers surveyed provided more than 20 hours of care a week and more than half had been providing care for six years or more.
- Although over 80% rated their health as excellent or generally good, 65% said providing care has had a negative impact on their health and wellbeing.
- Over 60% reported needing support in their caring role while 32% managed without help from others.
- While around 50% of staff reported fellow employees, managers and their employers to be supportive of their caring role, about a third chose not to disclose their caring role at work.
• About half of the respondents stated their caring role affected the hours and days they could work and their ability to do shift work or extra shifts.

• Seventy five per cent of respondents reported caring impacted on their need to access Sick, Annual or Long Service Leave entitlements; and while over half reported no difficulty in requesting leave in relation to their caring role, over one third had experienced difficulty.

• Just under one third of responses identified the impact of caring on the Carer as an education need for Health Professionals. Over a third (39%) identified a need for education of staff who are Carers about Carer Services.

• One half of the key comments to the organisation or Chief Executive identified the need for workplace flexibility in relation to their caring roles. Sixteen percent identified education of Health Professionals as a need, 14% identified the establishment of a register of employee Carers and 13% identified the need for ongoing support of Carers in our Organisation and Communities.

Noteworthy is that the majority of the staff responding to the survey felt supported by our organisation and this was acknowledged in freehand comments. A large minority was or chose to remain hidden to the workplace. Not all staff felt supported and responses also noted how support could be improved.

Implications of the Report

The report has important implications for the Districts in relation to the roles of Public Sector Agencies and human service Agencies stated in the NSW Carers’ (Recognition) Act 2010. Under the terms of the Act, LHDs have obligations to ensure that all staff have an understanding of the Charter and take action to reflect its principles, consult with Carers on policy issues that may affect them and that human resource policy caters to the needs of the LHD workforce who are Carers.

This report serves as a benchmark for other LHDs in NSW. Expressions of interest in the results have been received from external and internal stakeholders and Northern Sydney LHD has replicated the On Line survey. The survey results reflect SLHD and SWSLHD support for staff who are Carers and provide a basis to institute change.

The report makes eight recommendations for action. The recommendations are informed by the survey findings and analysis.

Implementation of the recommendations will strengthen the LHDs ongoing commitment to the priorities in the NSW Carers Action Plan 2007 – 2012. In addition, implementation of the recommendations is an important part of the LHDs’ initiatives to ensure compliance with the NSW Carers Recognition Act 2010.
“I feel I burden my colleagues when I am not able to go to work as there is never any reliever and they have to share my work load. Often my RDO’s are used to take my parents for their medical appointments so I don’t take too much time off work.” SSWAHS employee

The depth of information and sincerity in expression is of enormous benefit to the organisation. Thank you to our Carers for their openness and for creating awareness and providing insight into their experiences and challenges of combining working and caring. We acknowledge their courage in facing each day to do what they do.

Amanda Larkin
Chief Executive
South Western Sydney Local Health District
1. Introduction

“Often caring is very rewarding and should not be viewed just as a burden”

This chapter details the context of this report which focuses on Carers as a key policy concern, the purpose of the report, addresses for whom it is written, provides a conceptual framework for sustainable support of staff who are Carers, links the SWSLHD and SLHD Carers Action Plan to other plans and provides a guide to interpreting figures.

1.1 Context of this Report

“…That future is one in which demographic trends – an ageing population and changes in family structures – will see three out of five people caring at exactly the same time as the economy will need more of us to work longer”\(^1\)

An increasing focus on the needs and importance of Carers in the last two decades by Carer advocates and political lobbyists in Australia has resulted in increased public awareness and recognition of the need to provide effective support. This focus is in accord with trends in the United Kingdom (UK) where the Carers (Recognition and Services) Act 1995 first legally defined the term Carer and introduced the concept of Carer assessment. The late 1990’s saw the roll out of a national strategy for Carers which focused on information provision to Carers and services to support them. The UK Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act (2004) followed to further address Carers’ rights; the latter placing a statutory duty on Social Services Departments to inform Carers of their rights. As well, the Employment Relations Act (1999), the Employment Act 2002 and the Work and Families Act (2006) introduced legislation providing some protection to Carers from employment disadvantage and discrimination.\(^2\)

In Australia similar changes in legislation and government regulations have established guidelines relating to Carers. Anti-discrimination law\(^3\) ensures workers with family caring responsibilities have flexible working needs addressed and National Employment Standards\(^4\) specify the right of a worker to ask to work from home if they have preschoolers or a disabled child.

The Australian Bureau of Statistics (ABS) publication A Profile of Carers in Australia\(^5\) notes “Concern for the wellbeing of Carers, and an appreciation of the value of work they do, has made Carers a key social policy concern. Carers enable older people to ‘age in place’ and people with a disability or long-term illness to remain in the community.”

Further, in 2010 the NSW Carers (Recognition) Act\(^6\) was proclaimed to ensure the rights of Carers are met. This Act includes a charter of Carer rights and specifies how Public Service Agents and Public Service Care Agents must meet obligations in relation to the Charter. Obligations of public sector agencies are to:

- Take all reasonable steps to ensure that the members of staff and agents of the agency have an awareness and understanding of the NSW Carers Charter;
• Consult with such bodies representing carers as the agency considers appropriate when developing policies that impact on carers;
• Develop internal human resources policies having due regard to the NSW Carers Charter, so far as they may significantly affect the role of a member of staff of the agency as a carer.

Additional obligations of human service agencies are to:
• Take all reasonable steps to ensure that the agency, and the members of staff and agents of the agency, takes action to reflect the principles of the NSW Carers Charter.
• Prepare a report on its compliance with this Act in each reporting period. The report must be included in the agency’s annual report for the reporting period.

The ABS 2006 census indicates there were 100,743 people (9.7%) aged over 15 years in SSWAHS who provided unpaid help, care or assistance to a family member or other because of a disability, long term illness or problem relating to old age.

As well, the Commonwealth Government has recognised that Australia’s society is ageing. Retirement ages have been adjusted to provide greater economic security with women expected to work an additional 10 years before retirement. The number of women in Australia’s workforce is increasing. Health services are a major employer of female staff (76.2%). The need to contain increasing health costs has led to government recognition of the importance of supporting Carers (who are mainly women). In Australia, the economic value of the contribution of informal Carers to the Australian economy has been estimated at over $40 billion a year, if all the care was to be replaced by formal services.

In the UK some culturally and linguistically diverse (CALD) Carer groups have high levels of caring, especially at younger ages. This suggests these Carers may face additional barriers in accessing paid employment and career opportunities. SLHD and SWSLHD have large CALD populations. Forty percent speak a language other than English at home compared with 26% in NSW. In Canterbury and Fairfield Local Government Areas over 60% of the population do not speak English at home. It is therefore likely that similar conditions to the UK apply. In SWSLHD staff from CALD backgrounds make up 34.1% of the workforce and in SLHD 39.5%.

This cultural diversity in SWSLHD and SLHD residency and workforce has implications for allocating funding appropriately, planning and delivering local services to Carers and for providing support to staff who are Carers.

1.2 The Purpose of This Report

The purpose of this report is to:
• Showcase results from various surveys of staff who are Carers across the former Sydney South West Area Health Service (SSWAHS);
• Identify Carers concerns in combining workplace and caring responsibilities;
• Identify gaps in workplace support of staff Carers;
• Meet the KPIs of the SSWAHS Carers Action Plan;
• Provide recommendations on future actions to support staff who are Carers. The project lasted from November 2005 to January 2011. It was in response to increasing concern from many groups that had interest in Carers issues. The aims of the project were to assess the needs of staff who are Carers and the workplace support for these Carers. The scope of the project was targeting staff who are Carers in both LHDs. Strategies have been put in place for Carers in our communities and to engage Carers in patient care in health facilities. As well, policies have been provided to guide work with Carers in public sector agencies. However, not much is documented about the needs of staff who are Carers in LHDs, particularly SLHD and SWSLHD. Anecdotal comments suggest that more could be done to support staff who are Carers that would benefit our organisation enormously.

1.3 For Whom Is This Report Written

This report is written for internal and external stakeholders who have an interest in seeing Carers combine their working and caring roles successfully. Many of these stakeholders also have a commitment and obligation under the NSW Carers (Recognition) Act to support Carers who work for them and to whom they provide services. Some of these include:

• LHD Human Resources;
• LHD Carer Support Services (Carers Programs);
• Line managers of staff Carers;
• LHD Boards;
• The Centre for Education and Workplace Development (development of on-line learning);
• Other LHDs;
• The Ministry of Health, Department of Family and Community Service and other Public Sector and human service agencies.

Survey results provide valuable insights from Carers that can guide policy and procedures in human resource management (particularly around matters of Leave) and staff education focusing on the needs and treatment of Carers in contact with our services. This may mitigate Carers being discriminated against in their workplace because of caring responsibilities outside work.

1.4 A Conceptual Framework for sustainable support of ‘Staff who are Carers’

This framework provides a snapshot of the past, present and future pathway to embed support for Carers in the LHD. It covers a range of materials based on the following:

• Staff who are Carers in the SLHD and SWSLHD;
• Carer and Caree in the context of work;
• Previous surveys or research or literature whose methodology achieves validity, consistency, reliability, standardisation, soundness and completeness;
• Reputable sources within and external to NSW;
• Various NSW public sector plans.
1.5 Links to other Plans and Reports

This report links to a range of plans, frameworks and reports. While recognising that these plans, frameworks and reports belong to varying levels of government, meeting Carer needs, including working Carers form part of their key performance indicators. They include:

**NSW Carers Action Plan 2007 – 2012**
Reflects the five Priorities for Action
1. Carers are recognised respected and valued
2. Hidden Carers are identified and supported
3. Services for Carers and the people they care for are improved
4. Carers are partners in care
5. Carers are supported to combine caring and work

**SLHD and SWSLHD Carers Action Plan 2007 – 2012**
Articulates with the five priorities of the NSW Carers Action Plan and triggers the development of a generic Carer friendly model of care which aids the identification of gaps and ensures a planned, effective and systematic approach to working with Carers.
NSW State Plan a New Direction for NSW (2006)
A ten year plan which outlines the goals for the NSW Government: Rights, Respect and Responsibility; Delivering Better Services; Fairness and Opportunity; Growing Prosperity across NSW; and Environment for Living. The plan priorities include attention to Carers: improved access to quality health care (S1); improved survival rates and quality of life for people with potentially fatal or chronic illness through improvements in health care (S2); improved employment and community participation for people with disabilities (F2); improved outcomes in mental health (F3); and reduced avoidable hospital admission (F5).

NSW State Health Plan A New Direction for NSW Towards 2010 and Beyond
The NSW State Plan A New Direction for NSW (2006) - The NSW State Health Plan A New Direction for NSW Towards 2010 and beyond reflects the health priorities in the NSW Government’s State Plan. It contains strategies to be implemented by NSW Health to address these goals with equity in health a fundamental principle. In particular, the plan includes a focus on Carers within the key strategic areas of creating better experiences; strengthening primary health, continuing care in the community; and building a sustainable workforce.

Future Directions for Health in NSW – Toward 2025 Fit for the Future
Future Directions for Health in NSW – Toward 2025 Fit for the Future outlines seven long-range future directions for the NSW health system over the next twenty years.

The NSW Government Stronger Together; A new direction for disability services 2006 – 2016
The NSW Government Stronger Together: A new direction for disability services 2006 – 2016 focuses on disability services and emphasizes three major target areas: strengthening families; promoting community inclusion; and improving the system’s capacity and accountability. This plan focuses primarily on services funded through the Department of Family and Community Services but will have implications for health services which work with this Department.

The NSW Government Better Together: A New Direction to Make NSW Government Services Work Better for People with a Disability and Their Carers 2007 – 2011 is a whole of government plan which focuses on delivering better services for people with disability, their families and Carers.

Unpublished report on Carer Complaints in SSWAHS
This unpublished report covers specific complaints made by Carers to the SSWAHS in 2010 which identifies lack of staff awareness in providing care to elderly people and people with disability.

1.6 Guide to Interpreting figures
The Conceptual Framework for Sustainable Support of Staff who are Carers (1.4) provides a snapshot of the past, present and future pathway to embed support for Carers in the LHD.
This report is at the fourth phase of a seven-step process supporting staff to combine caring and work.

“Carer” is defined as a family member or friend who provides ongoing support to children or adults who have a disability, mental illness, chronic condition or who are frail aged (Carers NSW). The term ‘Caree’ refers to the person the staff member looks after. In the context of this report, a Carer is not a parent who is caring for a dependent child unless that child also has an illness or disability and the term does not refer to a care worker who is paid to provide care in the home or community.

Pilot surveys were carried out at the Canterbury Hospital (TCH) and Community Health Services in August 2007 and at Concord Repatriation and General Hospital (CRGH) and Centre for Mental Health in October 2008. The Online Survey (OL) was posted on the SSWAHS intranet from October 2010 to January 2011.

Results displayed in tables from the pilots and OL survey, are reported separately due to the elapse of time between each pilot and the OL survey. Percentages quoted in the body of the report and related discussions are based on OL results unless otherwise specified. Percentages recorded to one decimal point in tables are rounded to whole percentages in other parts of the report.

Online results are probably most reliable given the number of respondents (329). However, the limitation to this survey is that not all SLHD and SWSLHD staff have access to computers to complete the online survey whereas surveys were stapled to the pay slips of all staff at the pilot sites. Nurses, for example, who are predominantly female, make up 45% of LHD workforces but often lack ready access to computers because of their limited availability on wards. Nurses who are carers may therefore be underrepresented in the survey data. As well, older staff who are carers may be less computer literate and could also be underrepresented.

Staff may also not have been as comfortable completing the OL survey due to concerns regarding anonymity.

Freehand survey responses were collated based on themes. However these responses do not necessarily correlate to the number of respondents. In the tables, freehand data is quantitative when reflecting the percentages of responses about a subject and qualitative when examining the content of those responses.

Survey results have been compared to national trends in the ABS publication - A Profile of Carers in Australia (2008). This profile is based on the 2006 Census of Population and Housing and from three ABS surveys: the 2003 Survey of Disability, Ageing and Carers (SDAC); the 2006 General Social Survey (GSS) and the 2006 Time Use Survey (TUS).

In respect to language spoken, respondents were asked what language they spoke most of the time at home.

Endnote system of referencing has been used to cite sources of facts or opinions used in this report. Primary References are also listed in Chapter 10.
2. Methodology

“*My manager has always tried to accommodate my needs so I can continue to work and attend to caring responsibilities*”

At the inception of the Carers’ Program in 2005 the then Carer Support Service team became increasingly aware of;
- Australia’s ageing society and therefore ageing workforce
- The increasing number of women working generally in the work force as well as the predominance of women working in SSWAHS and other health services;
- The increasing need for family/informal Carers (who are mainly women) and;
- Increasing health costs.

It was pertinent to establish a work plan and key performance indicators and benchmark the organisation’s support for Carers against state and national standards. An informal organisational assessment was carried out and the team identified a lack of knowledge about working Carers.

The developed work plan focused on five areas:
- Estimating how many staff identified themselves as a Carer;
- Identifying staff concerns in combining workplace and caring responsibilities;
- The workplace support for these Carers;
- The gaps in this support and;
- How these gaps might be addressed.

The team also believed that this information would have value for workforce development programs and management of human resource.

An initial literature review was carried out to ensure team concerns were supported by research. In consultation with staff who were Carers, the Carers’ Program team developed 39 survey items to gain quantitative and qualitative information on:
- Demographic details about the Staff Carer and their Caree;
- Impact of caring on Carer health, wellbeing, social life and leisure;
- Workplace and community support for the Carer;
- Impact of caring on work;
- Access to leave and Carer entitlements;
- Education and resource needs of Carers and health professionals.

Seven items provided opportunity for respondents to make freehand comments. See Appendix 1 for the survey template.

Ethics Review Committee approval ensuring respondent anonymity at all stages of collecting, collating and reporting data was obtained on December 14th 2005 to survey staff who were Carers by attaching surveys to all employees’ pay slips at Area Health facility pay distribution points. Staff who were Carers were asked to complete the survey and return it to the SSWAHS Carers Program using the AHS’s internal mail system.
Pilots of the “Improving Support for Staff who are Carers” survey were conducted by attaching surveys and pre-addressed return envelopes to all staff pay slips at TCH in August 2007 and CRGH in October 2008. This was to ensure anonymity and encourage free expression. Prior to this the team designed and developed promotional posters to generate awareness about the existence and distribution of the survey. These were displayed in strategic positions throughout the Canterbury Community Health Centre, TCH and CRGH hospitals two weeks before commencing the pilots. Responses were received through internal mail and collated electronically. The results were made available to the General Managers of both hospitals as well as to the members of the Area Carers’ Action Plan Implementation Committee.

The team now planned to run an organisation-wide survey of all staff to obtain a complete picture of staff who are Carers. It also intended to look at relevant literature from organisations that have surveyed their staff either locally, Inter-state, nationally or internationally.

The release of the NSW Carers Action Plan 2007-2012 naming the support of working Carers and the identification of hidden Carers as key priorities in the plan lent further weight to the survey’s relevance.

Completion of the survey was therefore included as a strategy in the then SSWAHS Carers Action Plan and a partnership was set up between the Area Carers’ Program, Workforce Planning and Development and Human Resources who were deemed jointly responsible for implementing the survey in the Action Plan (Summary Action Table p4 5.4).

Consultation with Senior AHS staff on the then SSWAHS Carers Action Plan Implementation Committee established that an On Line survey of staff would be more feasible than distributing the survey via pay slips. This alternative would still allow the organisation to meet the KPIs of the Action Plan. Ethics approval was gained for the new approach.

In October 2010 the Carers’ Program and Strategic Workforce Planning & Development of the Sydney South West Area Health Service (SSWAHS) now South Western Sydney and Sydney Local Health Districts (SWSLHD & SLHD) conducted an On Line survey of employees who are Carers.

In line with the pilot surveys, the aim of the project was to identify hidden Carers, current support, gaps and recommendations of how to close these gaps across the organisation. A further literature review was conducted and out of 450 articles 16 articles were found to be most relevant to the survey. These have been referenced throughout this report using Endnote system of referencing to cite sources of facts or opinions. They range from Employer surveys of health staff who are Carers to research into provision of support structures in private companies.

The six top research articles used in this report are:
- A Profile of Carers in Australia
- Who Cares Wins: The social and business benefits of supporting working carers
- Managing Caring and Employment
• Educational Needs of Employed Family Caregivers of Older Adults
• Evaluation of a Workplace Project and;
• Carers Employment and Services: Time for a New Social Contract?
(Full details of these articles can be found in endnotes and references)

The online survey was placed on the LHDs intranet for three months from October 2010 to January 2011. Survey items were replicated from the Pilot surveys with minor changes to item numbering to allow adaptation to the SSWAHS online survey tool, a different software application to that used for the pilot surveys. A report of online responses based on the Carer and Caree was generated and analysed along with similar reports from the two pilot surveys. Freehand responses were categorized according to subject themes. Due to the large number of free hand responses, further analysis was necessary to establish dominant themes across these categories.
3. Data Analysis

“People who are not exposed to being a Carer – do not understand the commitment or physical work load”

Thirty three staff who are Carers responded at TCH, 77 at CRGH and 329 to the OL survey. Of 23,200 staff in SSWAHS, 1.4\%\textsuperscript{13} responded to the latter survey.

DEMOGRAPHY - Tables 1.1 to 1.4

Collection of data on the characteristics of staff Carers showed:
- 41\% of Carers were aged between 46 and 55 years;
- 89\% were female;
- 64\% worked full time;
- 33\% worked part time;
- 2.4\% were of Aboriginal or Torres Strait Islander descent;
- 26\% came from a CALD backgrounds;
- 83\% spoke English at home most of the time;
- 31 other languages were spoken by those not speaking English;
- The top 5 languages other than English (LOTE) spoken at home were Spanish, Vietnamese, Filipino, Cantonese and Hindi.

CAREE CHARACTERISTICS - Tables 2.1 to 2.4

Similarly, data collection on the characteristics of the Caree showed:
- 41\% of staff Carers were caring for their parents;
- 34\% were caring for children;
- 29\% specified the main condition of their Caree to be frail aged;
- The top 5 conditions specified were frail aged, developmental disability, mental health, heart condition/stroke and dementia;
- 62\% of Carees lived in the Carer’s home;
- 47\% of Carers provided more than 20 hours of caring a week;
- 29\% of Carers had been providing care for between 3 – 5 years.

IMPACT ON HEALTH, WELLBEING AND SOCIAL LIFE ETC - Tables 3.1 and 3.2

It was envisaged that there might be differences between the impact of caring on working Carers in health services and the general caring population:
- 81\% of staff Carers rated their health as excellent or generally good;
- 65\% said providing care had a negative impact on their health and wellbeing;
- Of the 65\% above, 31\% stated an impact on emotional wellbeing, 23\% on sleep patterns and 21\% on interpersonal relationships;
- 36\% reported their caring role impacted on their social life all or most of the time.
CARER SUPPORT FROM THE COMMUNITY - Tables 4.1 to 4.3

It was important to explore sources of support that may have enabled staff Carers to continue their dual roles of working and caring:

- 61% reported needing support in their caring role;
- 63% reported Friend/Relative/Spouse to be their source of support;
- 28% reported Community Services.

Of those staff Carers not receiving support:
- 32% reported managing without help;
- 21% reported the Caree refused other help;
- 15% reported they did not know where to obtain help;
- 15% reported they were not eligible for help.

WORKPLACE SUPPORT (employer/line manager/colleague support) - Tables 5.1 and 5.2

One of the most important aims of the survey was to ascertain whether staff Carers perceived the organisation to be supportive of working Carers:

- 60% said their fellow employees were supportive of their caring role;
- 54% said their managers were supportive;
- 44% said their Employer was supportive;
- 33% did not disclose their caring role to fellow employees;
- 28% did not disclose their caring role to their managers;
- 39% did not disclose their caring role to their employer;
- 44% of qualitative comments stated their workplace to be understanding.

IMPACT OF CARING ON WORK - Tables 6.1 and 6.2

It was also considered important to explore how caring impacted on staff Carers’ work:

- 51% said their caring role impacted on hours/days they could work;
- 57% said their caring role did not impact on their ability to work full-time;
- 42% said their caring role impacted on their ability to do shift work;
- 49% said their caring role impacted on their ability to do extra shifts;
- 71% stated their caring role had no impact on other employees;
- 40% of freehand responses commented about the need to take leave for caring responsibilities.

ACCESS TO LEAVE - Tables 7.1 and 7.2

It was anticipated that a caring role outside work would have an impact on staff Carers’ need for leave and that consequent issues might arise in accessing this leave:

- 75% said their caring role impacted on their need to access Sick, Annual Leave or Long Service Leave (LSL) entitlements;
- 55% stated they had no difficulty in requesting Carers or other leave for reasons related to their caring role;
- 37% stated they had experienced difficulty;
Stated below are key reasons for difficulties experienced (n =199):
- 23% were unsure of their entitlements;
- 22% had insufficient leave;
- 10% were unsure about the process to access leave;
- 9% indicated their leave was not approved.
- 28% of qualitative responses stated the Manager/other staff to be unsympathetic/inflexible regarding the Carer’s need for leave;
- 20% of qualitative responses stated they had used all leave entitlements in their caring role.

ACCESS TO GOVERNMENT ENTITLEMENTS FOR CARERS\textsuperscript{14} - Table 8.1

The survey elicited information about staff Carers’ access to government entitlements:
- 70% said they were aware of their entitlements;
- 16% said they were unaware of their entitlements;
- 14% said they were not sure of their entitlements.

Of those staff Carers aware of their entitlements:
- 52% were not eligible;
- 29% were eligible;
- 19% were already receiving entitlements;

EDUCATION NEEDS OF CARERS - Table 9.1

Responses provided insight into staff Carers’ educational needs:
- 39% of staff Carers’ comments identified a need for education about Carer services;
- 18% identified Taking Care of Yourself (Caring/Life Balance);
- 15% identified Accessing Leave and Leave Entitlements.

HEALTH PROFESSIONALS’ EDUCATIONAL NEEDS - Table 10.1

The survey also provided a unique opportunity to canvas staff Carers about the educational needs of health professionals providing services to Carers and their Carees:
- 30% of staff Carers’ comments identified The Impact of Caring on the Carer as an education need;
- 14% identified Empathy for Carers in their Caring Role;
- 13% identified How to manage/care for a person with disability;
- 12% identified options for Carer services in the community.

KEY COMMENTS FROM STAFF CARERS TO THE ORGANISATION/CE - Table 11.1

Opportunity was provided for staff Carers to comment further about support the organisation could provide:
- 48% of staff Carers’ comments identified the need for Increase workplace flexibility;
- 16% identified education of Health Professionals as a need;
• 14% identified the establishment of a register of employee Carers;
• 13% identified the need for ongoing support of Carers in our Organisation and Communities;
• 3% made comments that were beyond the scope of the survey.
## DEMOGRAPHICS

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<th>Table 1.1</th>
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<th>CRGH</th>
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<td>%</td>
<td>%</td>
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## CAREE CHARACTERISTICS

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<tr>
<td><strong>Hrs/Wk Providing Care</strong></td>
<td>%</td>
<td>%</td>
<td>%</td>
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<td>5 - 10</td>
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<td>11 - 15</td>
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### Table 3.1

<table>
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<th>Self-Rating of Health</th>
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<tr>
<td>Excellent</td>
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<td>11.7</td>
<td>10.7</td>
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<tr>
<td>Generally Good</td>
<td>60.6</td>
<td>72.7</td>
<td>70.4</td>
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<tr>
<td>Not So Good</td>
<td>21.2</td>
<td>11.7</td>
<td>18.0</td>
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<tr>
<td>Poor</td>
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<td>0.9</td>
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<tr>
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### Table 3.2

<table>
<thead>
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<th>Impacts</th>
<th>TCH</th>
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<th>OL</th>
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<td>Physical Injury</td>
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<td>1.1</td>
<td>2.6</td>
</tr>
<tr>
<td>Generally Physical Health</td>
<td>15.2</td>
<td>21.3</td>
<td>14.3</td>
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<tr>
<td>Sleep Patterns</td>
<td>18.2</td>
<td>22.5</td>
<td>21.3</td>
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<td>Emotional Wellbeing</td>
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<td>30.3</td>
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### Table 3.3

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### Table 4.1

<table>
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<th>Support Needed</th>
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<tr>
<td>Yes</td>
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<td>50.7</td>
<td>61.1</td>
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<tr>
<td>No</td>
<td>33.4</td>
<td>48.0</td>
<td>38.9</td>
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<tr>
<td>No response</td>
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<td>1.3</td>
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### Table 4.2

<table>
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<th>Reason Receiving No Support</th>
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<th>CRGH</th>
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<tr>
<td>Manage without help</td>
<td>72.7</td>
<td>57.1</td>
<td>31.9</td>
</tr>
<tr>
<td>No one Willing/Able to help</td>
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<td>12.3</td>
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<tr>
<td>Caree Refuses Others Help</td>
<td>18.2</td>
<td>5.7</td>
<td>20.6</td>
</tr>
<tr>
<td>Do not qualify for help</td>
<td>9.1</td>
<td>14.3</td>
<td>14.7</td>
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### Table 4.3

<table>
<thead>
<tr>
<th>Comments About Support Received</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
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<tr>
<td>Agency Assistance Problematic</td>
<td>42.8</td>
<td>38.5</td>
<td>42.3</td>
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<tr>
<td>Hard for Carer/Family to Provide</td>
<td>28.6</td>
<td>15.4</td>
<td>20.5</td>
</tr>
<tr>
<td>Career or family able to meet need</td>
<td>14.3</td>
<td>23.0</td>
<td>16.6</td>
</tr>
<tr>
<td>Agency Assistance provided</td>
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<td>10.3</td>
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<tr>
<td>Flexible work practices not provided</td>
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<tr>
<td>Support groups helpful</td>
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<tr>
<td>Comment not related to support received</td>
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<td>7.7</td>
<td>6.4</td>
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*Table 4.2 provides data on the % of respondents, table 4.3 provides data on the % of responses to freehand survey item 16c (see appendix 9.1)*
### EMPLOYER/LINE MANAGER/COLLEAGUE SUPPORT

#### Table 5.1

<table>
<thead>
<tr>
<th>Employer Sympathetic</th>
<th>TCH</th>
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<tr>
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<td>No</td>
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<tr>
<td>Not Aware of Role</td>
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<td>37.7</td>
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<td>12.1</td>
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<td>17.6</td>
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<td>Unaware of caring Role</td>
<td>24.2</td>
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<tr>
<td>No Response</td>
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<thead>
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<th>Colleagues Sympathetic</th>
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<tr>
<td>Yes</td>
<td>45.5</td>
<td>45.5</td>
<td>59.9</td>
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<td>Unaware of Caring Role</td>
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<td>32.2</td>
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<td>14.3</td>
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#### Table 5.2

<table>
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<td>Workplace is understanding</td>
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<td>44.0</td>
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<td>Workplace is not helpful/understanding</td>
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<td>Some Manager ok/some not</td>
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<td>7.2</td>
<td>9.2</td>
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<td>Carers not looking for Sympathy</td>
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<tr>
<td>Most/all workplace unaware of caring role</td>
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<tr>
<td>Workplace aware but not understanding</td>
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<td>7.3</td>
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<tr>
<td>Carer scared to ask for leave for caring role</td>
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<tr>
<td>No special entitlements for Carers</td>
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<tr>
<td>Insufficient leave entitlements apply</td>
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### IMPACT OF CARING ON WORK

#### Table 6.1

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<td>45.5</td>
<td>51.0</td>
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<td>45.6</td>
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<td>N/A</td>
<td>3.0</td>
<td>2.6</td>
<td>3.4</td>
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<td>No Response</td>
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<td>33.8</td>
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<td>32.5</td>
<td>25.5</td>
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<tr>
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#### Table 6.2

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<td>20.8</td>
<td>21.3</td>
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<tr>
<td>No</td>
<td>57.6</td>
<td>62.3</td>
<td>70.5</td>
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<tr>
<td>N/A</td>
<td>18.2</td>
<td>9.1</td>
<td>8.2</td>
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<th>Ability to work Full Time</th>
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<th>OL</th>
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<td>31.2</td>
<td>38.6</td>
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<tr>
<td>No</td>
<td>54.5</td>
<td>53.2</td>
<td>56.8</td>
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<tr>
<td>N/A</td>
<td>18.2</td>
<td>10.4</td>
<td>4.6</td>
</tr>
<tr>
<td>No Response</td>
<td>6.1</td>
<td>5.2</td>
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<table>
<thead>
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<th>Ability to do shift work</th>
<th>TCH</th>
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<th>OL</th>
</tr>
</thead>
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<td>28.6</td>
<td>41.6</td>
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<tr>
<td>No</td>
<td>42.4</td>
<td>38.4</td>
<td>31.3</td>
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<tr>
<td>N/A</td>
<td>27.3</td>
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### IMPACT OF CARING ON WORK (CONTINUED)

<table>
<thead>
<tr>
<th>Comments Regarding Impact on Work</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs to take leave for Caree needs</td>
<td>57.2</td>
<td>55.6</td>
<td>40.0</td>
</tr>
<tr>
<td>Caring prioritized over work</td>
<td>14.4</td>
<td>11.1</td>
<td>18.2</td>
</tr>
<tr>
<td>Impact on ability to work more hours/week</td>
<td>7.1</td>
<td>11.1</td>
<td>17.8</td>
</tr>
<tr>
<td>Unable to access flexible work practices</td>
<td>7.1</td>
<td>7.9</td>
<td>6.1</td>
</tr>
<tr>
<td>Able to access flexible work practices</td>
<td>7.1</td>
<td>6.1</td>
<td>6.1</td>
</tr>
<tr>
<td>Sometimes work must take priority</td>
<td>7.1</td>
<td>5.6</td>
<td>3.0</td>
</tr>
<tr>
<td>Needs Fulltime income</td>
<td>7.1</td>
<td>5.6</td>
<td>3.0</td>
</tr>
<tr>
<td>Other</td>
<td>7.1</td>
<td>11.1</td>
<td>4.2</td>
</tr>
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</table>

### ACCESS TO LEAVE

<table>
<thead>
<tr>
<th>Impact on Leave Days</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>51.5</td>
<td>48.1</td>
<td>74.5</td>
</tr>
<tr>
<td>No</td>
<td>27.3</td>
<td>40.2</td>
<td>22.8</td>
</tr>
<tr>
<td>N/A</td>
<td>12.1</td>
<td>7.8</td>
<td>2.7</td>
</tr>
<tr>
<td>No Response</td>
<td>9.1</td>
<td>3.9</td>
<td>2.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Difficulties Requesting Leave for Caring Role</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>18.2</td>
<td>20.8</td>
<td>35.9</td>
</tr>
<tr>
<td>No</td>
<td>45.5</td>
<td>48.3</td>
<td>53.2</td>
</tr>
<tr>
<td>N/A</td>
<td>24.2</td>
<td>24.7</td>
<td>7.9</td>
</tr>
<tr>
<td>No Response</td>
<td>12.1</td>
<td>5.2</td>
<td>2.7</td>
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</table>

<table>
<thead>
<tr>
<th>Difficulties Experienced</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>68.7</td>
<td>49.4</td>
<td>38.5</td>
</tr>
<tr>
<td>Unsure about entitlements</td>
<td>12.1</td>
<td>11.7</td>
<td>22.7</td>
</tr>
<tr>
<td>Insufficient Leave</td>
<td>3.0</td>
<td>5.2</td>
<td>22.1</td>
</tr>
<tr>
<td>Unsure about process to Access</td>
<td>6.0</td>
<td>28.6</td>
<td>10.3</td>
</tr>
<tr>
<td>Leave not approved by manager</td>
<td>5.2</td>
<td>9.4</td>
<td>2.7</td>
</tr>
<tr>
<td>Other</td>
<td>9.0</td>
<td>14.8</td>
<td>2.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comments about Difficulties Accessing Leave</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manager/Staff Unsympathetic/inflexible re: leave</td>
<td>14.3</td>
<td>15.0</td>
<td>27.5</td>
</tr>
<tr>
<td>Insufficient Leave for caring role</td>
<td>14.3</td>
<td>15.0</td>
<td>20.4</td>
</tr>
<tr>
<td>Unclear about leave entitlements/afraid to ask</td>
<td>14.3</td>
<td>30.0</td>
<td>12.0</td>
</tr>
<tr>
<td>Difficulty obtaining leave (mostly at short notice)</td>
<td>28.6</td>
<td>20.0</td>
<td>9.8</td>
</tr>
<tr>
<td>Process to approve Carers leave long/not flexible</td>
<td>14.3</td>
<td>5.0</td>
<td>7.8</td>
</tr>
<tr>
<td>Experienced guilt re: asking/taking leave</td>
<td>14.3</td>
<td>5.0</td>
<td>6.3</td>
</tr>
<tr>
<td>Responses not relevant to difficulties accessing leave</td>
<td>10.0</td>
<td>4.2</td>
<td>3.5</td>
</tr>
<tr>
<td>Required to provide Doctors certificate/stat dec</td>
<td>3.5</td>
<td>3.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Compromises work or client needs</td>
<td>3.5</td>
<td>3.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Inflexibility around hours worked</td>
<td>2.8</td>
<td>2.8</td>
<td>2.8</td>
</tr>
<tr>
<td>No staff replacement</td>
<td>2.1</td>
<td>2.1</td>
<td>2.1</td>
</tr>
</tbody>
</table>
### ACCESS TO CARER ENTITLEMENTS

<table>
<thead>
<tr>
<th>Access to Entitlements</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware of Centrelink Payments</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Yes</td>
<td>54.5</td>
<td>71.4</td>
<td>70.0</td>
</tr>
<tr>
<td>No</td>
<td>33.3</td>
<td>23.4</td>
<td>18.4</td>
</tr>
<tr>
<td>Unsure</td>
<td>6.4</td>
<td>5.2</td>
<td>14.0</td>
</tr>
<tr>
<td>No Response</td>
<td>6.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eligibility</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Yes</td>
<td>94.4</td>
<td>13.0</td>
<td>28.4</td>
</tr>
<tr>
<td>Yes and Receiving</td>
<td>19.5</td>
<td>15.9</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>5.6</td>
<td>59.7</td>
<td>19.1</td>
</tr>
<tr>
<td>No Response</td>
<td>7.8</td>
<td></td>
<td></td>
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</table>

### EDUCATION NEEDS OF CARERS

<table>
<thead>
<tr>
<th>Education Needs of Carers</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services Available to Carers</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Yes</td>
<td>50.0</td>
<td>40.6</td>
<td>39.1</td>
</tr>
<tr>
<td>No</td>
<td>40.0</td>
<td>40.0</td>
<td>39.1</td>
</tr>
<tr>
<td>Taking care of yourself (Caring/Life Balance)</td>
<td>11.1</td>
<td>15.6</td>
<td>18.3</td>
</tr>
<tr>
<td>Accessing Leave and Leave Entitlements</td>
<td>11.1</td>
<td>6.3</td>
<td>14.8</td>
</tr>
<tr>
<td>Education on Specific Conditions of Caree</td>
<td>22.2</td>
<td>31.3</td>
<td>8.7</td>
</tr>
<tr>
<td>Managing Balance of Working and Caring</td>
<td>5.6</td>
<td>3.1</td>
<td>6.9</td>
</tr>
<tr>
<td>Benefits Available to Carers</td>
<td>3.1</td>
<td>3.1</td>
<td>6.1</td>
</tr>
<tr>
<td>Understanding Dementia*</td>
<td></td>
<td></td>
<td>6.1</td>
</tr>
</tbody>
</table>

*A significant number of Respondents identified Dementia as an educational need*

### HEALTH PROFESSIONALS EDUCATIONAL NEEDS

<table>
<thead>
<tr>
<th>Health Professionals Educational Needs</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education &amp; Training for Health Professionals</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>The Impact of Caring on the Carer</td>
<td>16.7</td>
<td>24.3</td>
<td>30.4</td>
</tr>
<tr>
<td>Empathy for Carers in their Caring Role</td>
<td>21.6</td>
<td>13.9</td>
<td></td>
</tr>
<tr>
<td>How to manage/care for a person with a disability</td>
<td>8.3</td>
<td>18.9</td>
<td>13.1</td>
</tr>
<tr>
<td>Community options for Carer Services</td>
<td>33.4</td>
<td>12.2</td>
<td></td>
</tr>
<tr>
<td>Support needs of Carers</td>
<td>25.0</td>
<td>13.5</td>
<td>8.7</td>
</tr>
<tr>
<td>Carers as care partners (Recognising expertise)</td>
<td>6.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing good care to aged people</td>
<td>8.3</td>
<td>10.8</td>
<td>8.1</td>
</tr>
<tr>
<td>Impact of care recipients condition on family</td>
<td>6.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needs for managerial support for Carers</td>
<td>8.3</td>
<td>4.3</td>
<td></td>
</tr>
</tbody>
</table>

### KEY COMMENTS FROM STAFF CARERS TO THE ORGANISATION/CE

<table>
<thead>
<tr>
<th>Key Comments</th>
<th>TCH</th>
<th>CRGH</th>
<th>OL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase workplace flexibility</td>
<td>22.2</td>
<td>40.0</td>
<td>47.7</td>
</tr>
<tr>
<td>Health Professionals Education including Carer Burden</td>
<td>11.1</td>
<td>6.7</td>
<td>15.9</td>
</tr>
<tr>
<td>Establish register of employees Carers*</td>
<td>3.3</td>
<td>14.1</td>
<td></td>
</tr>
<tr>
<td>Support Carers in our organisation and communities</td>
<td>66.7</td>
<td>48.7</td>
<td>12.9</td>
</tr>
<tr>
<td>Education for Carers</td>
<td>5.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beyond Scope of Survey*</td>
<td>3.3</td>
<td>2.9</td>
<td></td>
</tr>
<tr>
<td>NSW Ministry of Health/LHD Carer Policy*</td>
<td>0.6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. Project Evaluation

“Absolutely, a hard but loving duty of care; Work is my escape – keeps me focused.”

Process Evaluation

The decision to implement the organisation-wide survey may have affected the response rate of staff who are Carers. Contrary to the Pilot surveys, the alternative option of an online survey did not guarantee access to all staff. However, it was considered to be a more feasible option by the SSWAHS Carers Action Plan Implementation Committee and Ethics approval was gained for the new approach.

A postal survey of 3,000 employees in a district health authority in the UK received 923 responses (a response rate of 31%)\(^\text{15}\). Adopting a similar approach may have yielded a better response rate than the District’s 1.4%. The data set was divided into quantitative and qualitative responses. Quantitative data was collated automatically by online software. However, collation of qualitative data was challenging due to the number of respondents, the enormous quantity of responses per question and the number of issues covered in the responses.

In both the UK and United States of America, differences have been found in the way caring impacts on employees’ work depending on their occupational level. In the UK, employees with “brains” (i.e. doing greater complexity of work) were more likely to report flexibility, responsiveness and sympathy from their employer\(^\text{16}\). In the US, executives and professionals were more likely to rearrange work schedules or reduce work hours whereas production workers were more likely to take unpaid leave because of less flexibility\(^\text{17}\). In subsequent review, this would be useful data to collect.

Impact Evaluation

It was clear that respondents to the survey felt acknowledged that the health service were seeking information about their circumstance and how it could best support them. This was reflected in the quantity and length of freehand comments. For example, 158 of 329 respondents provided comments about the impact of caring on work. In comparison, in the UK 80 freehand responses from 1,909 respondents was considered a significant number.\(^\text{18}\)

Outcome Evaluation

The project was successful in achieving its aims in that hidden Carers were canvassed and valuable insights gained into whether staff who are Carers felt supported. Other outcomes were the organisation is able to identify gaps in support perceived by Carers and recommendations Carers made to bridge these gaps.
5. Discussion

“No time or money to take care of my needs”
“I only talk about it if it comes up but I have managed to keep it separate from work”
“I have excellent support from my NUM and colleagues, both with work and emotionally”

This discussion focuses on themes, trends and where relevant a comparison of OL survey responses with various literature reviews completed including ABS figures.

The responses from staff who are Carers highlighted two very important points. Firstly the number that responded to freehand options in survey items was significant.

Secondly, the number who outlined their concerns in detail was also significant. It showed the issues raised in the survey were very important and relevant and reflected the strength of Carers’ feelings about these issues. These issues centred on flexible work practices, access to Leave, access to Carer-related information and services and education needs for themselves and health staff.

5.1 DEMOGRAPHY

In Table 1.1 Demographic figures for female Carers are higher than the National ABS figures because the workforce was predominantly female. Similarly, percentages are higher in 25 to 64 year age groupings as young Carers and aged Carers are likely to be underrepresented in a working population. Other than this, OL data on age, gender and Aboriginality (2.4%) reflect national trends. According to ‘A Profile of Carers in Australia’ women rather than men, were more likely to take on caring roles at an earlier age\(^\text{19}\). Therefore there is an urgent need for future strategies that increase workplace flexibility.

Consistent with 2006 National ABS figures which showed 26% of Carers to be overseas born, 25.8% of SLHD and SWSLHD respondents also identified as CALD. While ABS figures reported 83% speaking English well or very well, 69% spoke a LOTE at home. In this survey, while 25.8% identified as CALD, 83% spoke English at home reflecting that a significant number of respondents spoke English at home even though they identified as coming from other cultural or linguistic backgrounds. The highest proportion of CALD responses were received from Canterbury and the least from Concord. These surveys were conducted at different times and using different modes.

In table 1.3, of more significance than the top 5 LOTE spoken, is the total number of languages spoken. There were 27 languages including English spoken by OL respondents and 31 by both OL and Pilot respondents. This most likely reflects the diverse cultural background of people living and working in the South West of Sydney.
According to the SDAC\textsuperscript{20} survey report, 63\% of working age Carers were employed; of this figure, approximately 61\% worked fulltime and 36\% part time. Survey results were similar to SDAC statistics with 64\% of respondents working full time and 33\% part time. The SDAC report also notes that 48\% of primary Carers are employed but were more likely to work part time than full time due to the intensity of the care provided.

In the UK the circumstances of working Carers was analysed using two sources of secondary data; the 2001 Census and a national survey of working age Carers\textsuperscript{21}. It was found that many Carers had given up their paid job in order to care despite being of working age. There were also many Carers outside employment who wanted to work\textsuperscript{22}. It is highly likely circumstances for Carers are similar in Australia.

5.2 CAREE CHARACTERISTICS

Tables 2.1 to 2.4 detail the characteristics of the Caree relationship, the place of care, the health issue addressed by care provided and length of time and number of hours per week for which care is provided.

**Carer Relationship to Caree**

The OL results in Table 2.1 as well as the SDAC report grouped Carees mainly into partners, children or parents even though percentages varied. Other categories including siblings, In-laws and Neighbour/Friend are also specified. Table 2.1 shows in all survey locations the Caree-Carer relationship is most commonly a parent-child one. Please see Table 2.1 for more details.

**Main Conditions of Caree Specified by Carer**

The most common type of disability documented in the SDAC report was physical disability while frail aged was recorded for the TCH, CRGH and OL surveys.

OL responses in Table 2.2 reflected a nil response to Arthritis. This could be due to the software program restriction in the OL Survey which limited ability to display Arthritis as a preselected option. Although the next question provided opportunity for more conditions to be entered, respondents could have been satisfied with a preselected ‘frail aged’ option.

**Caree Residence**

In Table 2.3, 62\% of respondents lived with their Caree in the Carers home whereas the SDAC reported only 15\%. As frail aged was the most common condition of Carees, this may account for the variance of living situation. As well, as the OL survey only targeted working Carers, this may also account for the variance.
**Hours per Week and Number of Years Providing Care**

The highest number of hours (47%) recorded in ‘providing care per week’ was 20 hours and over (OL) despite their dual roles of working and caring. Although this varied between the TCH, CRGH and OL, the OL results were consistent with the SDAC figures despite differences in the grouping of the number of hours. The SDAC recorded 48% providing care at least equivalent to a traditional full-time paid job of 40 hours or more per week.

The highest percentage recorded to the question ‘number of years care provided’ in the OL (29%) and TCH (42%) was in the 3-5 age grouping; and CRGH (30%) was in the 11 – 20 age grouping.

UK evidence shows that those with more intensive caring roles have lower rates of employment. In addition as the number of years of providing care increases, so too does the likelihood of poor health and financial struggle. This group of Carers also felt they lacked information about services they needed\(^{23}\). Given the wide current acceptance of the need to support Carers, coupled with labour market demands needing people to work longer in Australia, SLHD and SWSLHD should aim to better support these Carers both in the workplace and elsewhere.

Labour market demands in Australia now require people to work longer before retirement. This has significance for working carers both physically and financially. Given the wide current acceptance of the need to support Carers, greater emphasis could be placed on supporting working Carers physical health and well-being. Health Service industries have adopted a risk management approach to occupational health and safety to reduce injury in workers who provide high levels of physical care as part of their work role. Working carers may further benefit from proactive assistance to maintain their physical capacities to both work and care. Well-being and health promotion programs that promote, for example, core muscle strength as well as safe manual handling strategies may particularly benefit working Carers.

Financial disadvantage caused by lower incomes and decreased superannuation contribution are outside of the scope of this report. However it may be pertinent for the matter to be raised at ministerial level for further discussion of whole-of-government strategies to address this disadvantage. A significant proportion of respondents indicated they are not eligible for government subsidies. Additionally, women (who make up the majority of Carers) may also take time off to raise children. Female Carers therefore face double disadvantage in establishing financial security.
5.3 IMPACT ON CARER HEALTH, WELL BEING, SOCIAL LIFE, HOBBIES AND LEISURE

“Emotionally, caring for my grandmother is a rewarding experience”

“My now grown up son is taller, heavier and stronger than me. He is more challenging to manage and his mental health more fragile. My own wellness is affected by the sheer physical aspects of his care”

The impacts of caring have been well documented in international and national research. In the UK; “Even among working Carers we found worrying numbers of Carers in poor health and struggling to make ends meet”24. A Profile of Carers in Australia notes caring may have positive as well as negative consequences (p38) and some OL respondents made freehand comments to this effect. SDAC report that about one-quarter (26%) of primary Carers felt satisfied as a result of the caring role and around one in ten primary Carers who had spouses, or other family members, had been brought closer to them. It was more common for Carers to be brought closer to the person they cared for more than to other family members.

However, 29% of primary Carers reported a change to overall physical and emotional wellbeing due to caring and about half of those who reported that their wellbeing had not changed had experienced at least one specific negative effect. Only 35% reported either no change to their physical and emotional wellbeing or no negative effects. Specific negative effects reported in SDAC were; weary/lacking energy (34%), worried or depressed (29%), angry or resentful (14%), sleep disruption (15%), losing touch/isolation (35%) and strained relationship with partner/lack of time together (34%).

While 81% of OL respondents (including primary and other carers) reported their health to be excellent or generally good, 65% reported their caring role had had a negative impact on their health and wellbeing. Of this 65%, 31% stated an impact on emotional wellbeing, 21% on sleep patterns, 20% on interpersonal relationships and 14% on generally physical health. Many Carers reported multiple impacts. Respondents also reported that caring responsibilities impacted on their social life, hobbies and leisure activities with 36% stating it impacted most or all the time and a further 57% stating it sometimes impacted. OL respondents also reported that caring had impacted in other ways with some free hand responses reflecting that respondents interpret “wellbeing” in a broader sense to encompass factors such as impact on work, career, finances, social participation and time demands.
5.4 CARER SUPPORT FROM THE COMMUNITY

“Assistance was available the on pretty pamphlets but when needed it was not available or there was a 1 year wait!”

Themes used to collate responses in the survey were phrased differently to those used in the Profile of Carers in Australia. Nevertheless, OL survey results again showed similar trends. In SDAC, about half of all primary Carers (253,000 people or 53%) said they had no major source of assistance. However, a substantial minority within this group (44%) did not need assistance. Among primary Carers who did receive assistance, relatives (other than their spouse), friends or neighbours were the most common source of assistance (40%), followed by spouses or partners (32%), and formal providers (28%).

Table 4.1 shows the majority of respondents in all locations reported the need for support in their caring role. Sixty three percent of those that needed no support stated their source of support to be family, friends or neighbours while 28% stated formal providers to be their source of support.

The Profile of Carers in Australia also note the importance of informal respite care and give reasons for Carers never having used respite (formal) care. They include ‘not needing it’, ‘Caree or Carer not wanting it’ and ‘respite care not being available, suitable or affordable’. In total, 17% of primary Carers said they needed access (or further access) to respite care.

Similar findings are reported in the UK. A national survey targeting working age Carers surveyed 1,909 Carers including 134 in face to face interviews, exploring their circumstances, experience and views. While most Carers (about two thirds working full-time and three quarters working part-time) were supported by family or friends, they also identified that working Carers often found that the services they needed either for their Carees or themselves, did not provide the help they required. Almost half of working Carers in the study reported that the lack of flexibility and sensitivity in the delivery of services was hampering them in obtaining support. “The support of flexible, sensitive and appropriate services, really make a difference to Carers yet many working Carers in this study felt there were significant weaknesses in the way local services were designed, delivered and made available...” 25 Reluctance to use services was often related to the way services were provided, the Carers’ lack of control involved in accepting services and the timing, frequency, flexibility and responsiveness of what was offered26. Given the degree of support already established for Carers in the UK through legislation and government policies27 it is likely similar gaps in service support exist in Australia.

Feedback from OL respondents in tables 4.2 and 4.3 reflected similar themes in the ‘reasons for receiving no support’ and in their comments about support. It is of concern that the most common reason for receiving no help (TCH- 43%, CRGH- 39%, OL-42%) was ‘Agency Assistance Problematic’.

Other reasons included;
- Carers managed without help/Carer or family were able to meet need;
- No-one was willing or able to help/hard for Carer or family to provide help;
- Caree refuses other help;
• Did not qualify for help/on waiting list for help;
• Agency assistance was problematic;
• Being unsure where to obtain help and;
• Lack of flexible work practices.

While beyond the scope of the survey, in the UK it has been found that a very large group of Carers needed more support than they are currently getting to help them manage their dual work and caring responsibilities\(^{28}\). It is likely that the situation is similar in Australia. It is also crucial that workplace efforts to improve the circumstances of working Carers are backed up by community resources that are local, person-centred, effective and responsive\(^{29}\).

### 5.5 Workplace Support

“I don’t tell them – personal and private family matters”

“Having worked at XXXX for 38 years I find the Area unbelievable the way we are treated. Managers understand babies and children but have no idea how hard it is being a carer”

“The impact of having an empathic and caring manager in the workplace cannot be over emphasised. While it can be open to exploitation it does facilitate caring at home and savings in the community”

The increasing emphasis on provision of Care in and by community, both in Australia and internationally, gives credence that this care should be supported by our employers.

Responses to a survey\(^{30}\) in the UK showed support from managers and colleagues is available to many working Carers; more than half the respondents reported that their employers were “Carer friendly”\(^{31}\). In the United States of America (USA), support has been provided by way of workplace care-giving (Carer) programs\(^{32}\) (see appendix 10.2)

In table 5.1 over 28% of staff (OL survey) who are Carers chose not to disclose caring responsibilities to colleagues, managers or their employer. Freehand comments suggest two principal reasons for this choice. Firstly, some Carers wished to keep the information confidential because they saw it as irrelevant to the workplace and secondly, some Carers had concerns that this knowledge might be used against them in accessing leave entitlements. However, the majority of respondents perceived colleagues (60%), managers (54%) and their employer (44%) to be either supportive of their caring role or to be unaware of it (Employer 39%). Results probably reflect respondents’ perceptions of closeness in relationship; with colleagues and managers more likely to be reported as supportive over employer and employer, less likely than managers and colleagues to be aware of their caring role.

Hiding caring responsibilities in the USA and UK appears from the literature to differ and to be more related to perceptions of discrimination. USA employees feared management would view them as “less promotable”\(^{33}\). In the UK some Carers felt employers were reluctant to take them on in the first place if they disclosed being a carer when applying for a job\(^{34}\).
In both countries, carer flexible work practices differed depending on the carer’s occupational status. In the UK, employees with higher status and more complex work were more likely to report flexibility, responsiveness and sympathy from their employer. In the US, executives and professionals were more likely to be able to rearrange work schedules or work reduced hours. Production workers however were more likely to be offered/ take unpaid leave because of less flexibility. The OL survey did not ask for respondents’ job title and so it could not be determined whether some staff reporting their managers as more sympathetic were in roles that were more complex. This would be useful data to collect in future surveys.

Freehand comments in regard to workplace support not only focused on the difficulties or lack of support created but also the positive difference workplace support made. Respondents characterised workplace support as;

- Managerial appreciation of their caring roles;
- Openness to staff members’ use of leave entitlements for caring responsibilities and;
- Willingness to employ flexible strategies such as early/late starts, long/short days, split shifts, term time working, make up time and time in lieu and work-from-home options.

In the UK, face-to-face interviews with Carers found employer support could include allowing some flexibility about how work is done, offering entitlements to leave or time off to care and breaks from work. However, it could also be primarily about treating employees with consideration respect and sympathy when problems in the care situation arise\(^{35}\).

In Sweden also “the need for support at work includes not only being entitled to take time off but also that one’s manager and colleagues understand the difficulty in managing multiple roles”\(^ {36}\). Providing social networks among staff who are Carers in workplace was also seen as an important means of easing the pressure of caring.

Though figures regarding workplace support are positive, data in table 5.1 still shows over 17% of respondents reported this was lacking. Respondents also provided in depth comment about lack of support, which suggests the need to improve practices around staff who are Carers. In organisations that developed and supported carer friendly approaches, staff who were carers identified how helpful these approaches were, both for themselves and in relation to business advantages for their employer. They identified skills learnt as a Carer that were transferable to the work place (time management and organisation), motivated, loyal and hard workers and happy and therefore, more productive workers\(^ {37}\).

5.6 IMPACT OF CARING ON WORK

In the 2003 Survey of Disability, Ageing and Carers, out of the 295,000 primary Carers who were not employed, almost one-third had left work just prior to taking on the caring role (31%). Just over half of primary Carers in this situation had left work specifically to start or increase care (51%); of all primary Carers who had left work to start or increase care, 38% had done so because alternative care was not available or too expensive, or because they were unable to change their working arrangements. However, the remainder had done so due to other reasons such as emotional obligations or because they preferred to care full-time (62%). Around 57% of male primary Carers who had left work to take on the caring role
had done so because alternative care was not available or too expensive, or because they were unable to change their working arrangements.

In the UK, while around a quarter of working Carers said their caring role did not affect their job, a significant number of working Carers had considered giving up work because of the stress of combining work and caring while others had resorted to working part time. Over 20% of working age Carers reported giving up work in order to care, 66% of Carers outside employment stated their caring responsibilities had caused them to leave paid work.OL survey results in Table 6.1 confirm the major impact of caring on work. Around half of respondents reported that caring impacted on the hours and days they were able to work or take on extra shifts; 42% and 39% respectively, reporting an impact on their ability to work shift work and fulltime. Freehand comments further emphasized these impacts with 40% of responses referring to the need to take leave to meet caring responsibilities; 14% of responses mentioned ability/inability to access flexible workplace practices as affecting the impact of caring on work.

It is important to recognise that work provides carers with a life outside of their caring role, as shown in some freehand comments. In the UK also, Carers have found that their workplace was somewhere they could foster individual identity and find respite from their caring role.

5.7 ACCESS TO LEAVE

“I was made to feel that I had to prove my father has cancer and was very ill. It felt like I was not believed.”

“I didn’t know about carers leave. I take annual leave when I need to take my father to hospital or a doctor. I feel quite guilty about it especially when it’s at short notice because my colleagues have to cover for my absence.”

As Table 7.1 shows, the majority of respondents (75%) reported an impact on accessing leave due to their caring role. Further, 35.9% also experienced difficulties in requesting leave for their caring role. Despite 53% of respondents having no difficulties requesting leave, the significant minority of respondents who did report difficulties (36%) and the large number of freehand responses further outlining these difficulties strongly suggests the organisation could provide better support.

Freehand comments in table 7.2 also emphasized some staff were not aware of their entitlement to Family and Community Services (FACS) and Personal Carers Leave (PCL). Further, a large minority of staff were unaware firstly, that PCL is a leave entitlement provided to all staff, not just staff who are Carers, and secondly, that PCL does not have a separate entitlement but is taken from the staff member’s Sick Leave, Annual Leave (AL) or Long Service Leave (LSL) entitlement. As there are no extra leave entitlements for caring responsibilities, there may be little cost implication for the organisation in responding more flexibly to requests for such leave. Furthermore, in the USA and the UK when working
Carers were offered flexibility to requests for Leave, the benefits to the organisation far outweighed the cost.

In Australia, Railcorp (NSW Transport) has established a register of employee Carers. This has reduced the need for working Carers to repeatedly provide medical certificates when leave from work is required to meet caring needs. SLHD and SWSLHD could also create a register of its staff who are Carers.

5.8 IMPACT ON LEAVE DAYS

In table 7.1, 75% of respondents reported caring responsibilities impacted on their leave days. While 53% reported no difficulties in requesting leave for caring responsibilities, a significant proportion did (36%). Freehand responses again reinforced while a large proportion of Carers reported no difficulty in accessing leave, others reported difficulties around manager/staff being unsympathetic or inflexible about leave (28%), having insufficient leave for caring role (20%), being unclear about leave entitlements or being afraid to ask (12%) and having difficulty obtaining leave especially at short notice (10%).

The impact of caring on respondents’ leave entitlements and access to leave was clearly a major issue with 88 freehand responses being received to this item. This is backed up by the SDAC survey where 32% of employed primary Carers reported they needed time off work for caring responsibilities.

5.9 ACCESS TO GOVERNMENT ENTITLEMENTS FOR CARERS

“Centrelink provide an insulting amount of financial assistance for carers and make them jump through hoops to get it. My mother cares full time for my disabled father and receives the equivalent to one night shift wage per week for this.”

Carer Payment is made by the Commonwealth Government to individuals who are unable to support themselves through substantial paid employment. This is because they are providing daily care to a person with a severe disability, medical condition or who is frail aged.

Similarly, Carer Allowance is paid to Carers providing the same care and attention to someone with a severe disability, medical condition or who is frail aged but is not means tested and can be paid in addition to wages or other income support payments. In a Profile of Carers in Australia, ABS, while the most common main source of personal cash income for Carers is wages and salaries, own business or partnership income (47% of all Carers), Carers are more likely than non-Carers to receive a government pension or allowance (40% compared with 24%) and around 57% of primary Carers reported a government pension or allowance as their main income source.

OL freehand responses indicated that for many Carers access to Carer entitlements was not relevant to them as they either chose to work or Carer entitlement was not considered sufficient income. In table 8.1 while 70% of OL respondents reported awareness of Carer
entitlements, 30% reported either not being aware or being unsure. Further, 30% of respondents reported not receiving benefits to which they were entitled. As most working Carers would not be eligible for Centrelink’s Carer Payment, it is likely that Carer Allowance is the benefit to which they are entitled but not accessed. While Carer Allowance is not means tested the process involved in applying for this entitlement may decrease the likelihood working Carers access it.

5.10 EDUCATION NEEDS OF CARERS

According to table 9.1 the top three subjects identified in respect to the education of Carers were; services available to Carers (39%), taking care of yourself/work-life balance (18%) and accessing leave and leave entitlements (15%). Other subjects listed were; education on specific conditions of Caree, managing the balance of working and caring, benefits available to Carers and understanding Dementia.

In the USA the top ten educational needs of working Carers were identified\(^4^4\). Three of these needs were remarkably similar to six needs identified OL (see table below):

<table>
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<tr>
<th>USA</th>
<th>OL</th>
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<tbody>
<tr>
<td>community resources</td>
<td>Services Available to Carers</td>
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<td></td>
<td>Benefits Available to Carers</td>
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<td>stress management</td>
<td>Taking care of yourself - Caring/Life Balance and</td>
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<td>managing balance of working and caring</td>
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<td>specific illnesses</td>
<td>Education on Specific Conditions of Caree</td>
</tr>
<tr>
<td></td>
<td>Understanding Dementia</td>
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Also in the United States, a Workplace Caregiving (Carer) Assistance Program\(^4^5\) was established. It included surveying and documenting the needs of Carers and implementing educational training sessions. The potential savings to the employer was USD$39,970.00. Other benefits included decreased employee lateness and absence for Caring activities, retention of valuable employees, fewer leaves of absences, less employee illnesses, benefit and enticement to new employees, stronger employee commitment to the job and increased employee productivity. The business and economic benefits to the organisation in supporting Carers will be discussed later in this chapter.

5.11 HEALTH PROFESSIONALS’ EDUCATIONAL NEEDS

“How it feels to do this 24/7”

“How health professionals often only treat patients for the condition for which they are in hospital. – They don’t recognise physical disability. Staff would organise someone to shower my husband but not help with meals; not role his sleeve down after taking blood.”
“Management of medications – we are not doctors so if we ask questions it would be nice to be answered politely and not dismissed. Patience, handwriting instructions not always easy to follow”

When asked to identify knowledge or training that would assist health professionals to support carers as a group a range of practical suggestions was provided. According to table 10.1 the top three subjects identified were:
- The impact of caring on the Carer (30%);
- Empathy for Carers in their caring role (14%) and;
- How to manage/care for a person with a disability (13%).

Other subjects listed were:
- The support needs of Carers;
- Carers as care partners (recognising expertise);
- Providing good care to aged people;
- Impact of care recipient’s condition on family and;
- The need for managerial support for Carers.

Responses provided insightful information on health professionals’ education needs in two ways. Firstly, these responses reflected their own experience as Carers. Secondly it reflected their concern as staff members who have observed how some health professionals treat Carers accessing our services. Freehand comments also identified that service provision to elderly people and people with disabilities could be improved (An analysis of Carer complaints made to the SSWAHS in 2010 also found this to be an issue). These insights provide a unique knowledge base that can contribute to future education of Health Professionals. In the UK, Carers have already identified the benefits to employers of working Carers who bring existing transferable skills such as multi-tasking and nursing care to the workplace.

The importance of addressing variance in local needs in relation to diverse CALD communities is also noted in the UK because some CALD communities have higher rates of caring than others. Given the large number of diverse CALD communities in the SLHD and SWSLHD catchments, this has significant relevance in relation to health professionals training and the delivery of health services.

5.12 KEY COMMENTS FROM STAFF CARERS TO THE ORGANISATION/CHIEF EXECUTIVE

“it’s good to get recognition from our employer”

“Thanks for the survey. Not sure if it makes me feel better or worse thinking about it all but it is nice that the organisation is interested - I hope not just Carer Centre people but also supported by HR”
The top 4 themes identified in Key Comments to the Organisation were; Increase workplace flexibility (47.7%), Health Professionals education including Carer burden (15.9%), Establish register of employee Carers (14.1%) and Support Carers in our organisation and communities (12.9%).

**Increase Workplace Flexibility**

In table 11.1 almost half of the 112 responses from staff Carers included comments regarding the need for **increased workplace flexibility** (see table 11.1). The survey findings show emphatically that workplace flexibility is largely dependent on line managers but application of flexibility varies. Staff who are Carers who work with an unsupportive line manager, find juggling work and carer responsibility extremely challenging. Conversely, those supported by their line managers commented on the difference this support made. Survey evidence strongly suggests that current leave policies and procedures do not reflect the practice of many line managers who are already using workplace flexibility sympathetically and effectively.

This is further supported in the UK where a study of a district health workforce surveyed approximately 3,000 employees and received 923 responses (31% response rate). Twenty two of those respondents volunteered for a follow-up group interview. The research found that along with accepting and supportive attitudes from their employers, the most helpful aspect at their workplace were flexible working hours. The report further detailed the importance of developing employment policies that support working Carers. In the UK it was found line managers attitudes and actions are central to the success of providing flexible workplace support. It was also found that even when flexible options needed to be limited because of the nature of the work in some parts of a business or organisation (such as a hospital ward or emergency department) employees expectations could be managed through induction content for new employees. There is variance in management practices around applying workplace flexibility. SLHD and SWSLHD could build on the initiative some line managers are already taking in fostering flexible work practices to improve policy and procedure and a culture that champions this flexibility. Also in the UK, the need to provide workplace support due to the double burden for working women - caring work and domestic labour - has been advocated. SLHD and SWSLHD with predominantly female workforces and a likelihood of future increased labour force demand, need to consider providing workplace flexibility and support.

**Health Professional Education including Carer Burden**

In Table 11.1 comments on the importance of **educating Health Professionals about Carers**, especially Carer burden are made in over 15% of responses. Along with data in Table 10.1 this emphasizes again how important this issue was to respondents. The unique opportunity provided to use working Carers’ insights to inform future education needs of Health Professionals has already been commented on earlier in this discussion.
Establish a register of Carers

In table 11.1% almost 16% of responses identified the need to establish a **register of staff who are Carers** - most often in the context of eliminating the need to repeatedly produce medical certificates to establish Carer leave entitlement. A register of employee Carers has already been successfully established in NSW\(^53\). In the UK, the anxiety caused by the need to prove a caring commitment by producing a doctor’s appointment card or hospital correspondence was identified as a barrier to flexibility. This requirement proved unnecessary and unhelpful\(^54\).

In LHDs, an application for Personal Carers’ Leave is required for every occasion of leave and a medical certificate, or statutory declaration (in the case of FACS leave), may be requested by the line manager. The establishment of a register of Carers would remove this time consuming barrier by reducing the burden of excessive paperwork when staff access Carer leave entitlements and provide tangible support to Staff who are Carers.

Support Carers in Our Organisation and Communities

In table 11.1 almost 13% of freehand responses emphasized the continuing need to **support Carers in Our Organisation and Communities**, particularly working Carers. These generic responses also commonly referred to the need to champion future efforts for positive change in developing Carer friendly policies, practice and discourse in the workplace, government sector, community and political arena.
6. Conclusion

In conclusion, this report is useful as it serves as a benchmark for other LHDs in NSW Ministry of Health. In particular, it underlines:

- The need for increased flexibility in relation to working options and leave entitlements;
- The benefits for staff who are Carers when line managers are supportive and sympathetic to their needs (and the disadvantages when they are not) and;
- The educational needs that if met, will support line managers, staff who are Carers and other health professionals to do their jobs.

There is now a strong evidence base in the UK\textsuperscript{55} that documents the benefits of workplace support for private and public sector organisations and the working Carers they employ. This research documents the positive results in both provision of business services and economic/profit advantages for small and large organisations in the public and private sector. It is noted that “their approach was by no means purely philanthropic.....there were also robust business logic behind the policies they were developing...”\textsuperscript{56} Support has been provided incorporating both dedicated carer friendly practices (such as special leave and work options) and the inclusion of working Carers in wider organisational strategies that champion diversity for all employees. An advantage of the latter approach is that adopting flexibility for all employees and empowering managers to be flexible, results in line managers being able to make decisions based on how business will be affected, without needing to make value judgements about whose needs are most deserving. Flexibility for all employees includes early/late starts, long/short days, split shifts make-up time, time in lieu, term time working, job-share and work-from-home options. However research shows that with either approach higher level support for culture change and line manager training to implement it is essential.

In Australia, Carers have also been helped by the establishment of carer supports that form part of a wider organisational approach to championing workplace diversity principles\textsuperscript{57}.

SLHD and SWSLHD can use this evidence to improve its performance in relation to all Carers, but particularly working Carers.

The UK evidence also led to recommendations not only about “the key role the state should play in providing appropriate frameworks” but also that “social care providers, health services, employers and the agencies responsible for the full range of other local services must work together in an integrated way to deliver a reliable infrastructure of support.”\textsuperscript{58} (See Appendix 9.3; the Infrastructure of Support for Carers) This report refers to Carers as an essential part of the “social fabric” and promotes a “social fabric approach” in bringing about future positive change for Carers, particularly working carers\textsuperscript{59}.

While these recommendations may go beyond the scope of the Improving Support for Staff who are Carers survey and the framework within which it was conducted, they nevertheless fit with the principles outlined in the NSW Carers (Recognition) Act 2010 and accompanying charter. Understanding the principles underlying these recommendations would strengthen...
SWSLHD and SLHDs commitment to fulfil public Sector and human service agency obligations outlined in the Act.

Expressions of interest in the SLHD and SWSLHD survey results have been received from external and internal stakeholders; the survey results reflect SLHD and SWSLHD’s existing support for staff who are Carers and provide a basis to institute change to address current gaps. Evidence from the OL survey and from research in the UK and Australia, form the basis of recommendations in this report.
7. Recommendations

Recommendations listed below align with the Conceptual Framework of Sustainable Support for Staff who are Carers (1.4) and are based on survey data analysis, particularly key comments to the organisation and on national and international evidence found in literature reviews:

1. **Establish procedures for staff who are Carers to be identified in the organisation and included on a Carer register so that, for example, medical certificates are not required for every application of PCL.**

   “It’s hard getting certificates from Drs, Dentist, Physios, Podiatrists etc. for treating my parents as my parents don’t use the same people”.

   This may include self-identification of working Carers on standard EEO data collection record at recruitment or manager identification when staff report a caring role or seek leave. Any register established should follow requirements for privacy and confidentiality regarding who has access to information it contains.

   A Carer register could also provide a basis for other workplace strategies to support Carers (See Appendix 9.3)

   **Responsibility:**
   LHD HR, Carers Program and relevant managers

2. **Provide easily accessible, plain English and user-friendly online information for all Carers (internet) and specifically SLHD and SWSLHD working Carers (intranet) about internal and external services in order to address obligations in the NSW Carers (Recognition) Act 2010.**

   **Responsibility:**
   LHD Carers’ Program and CEWD

3. **Review and promote easily accessible, plain English and user-friendly on-line training options (either internal, other LHD or NSW MoH), for Health Professionals who provide support services to Carers as part of their role.**

   They should include information on:
   - services for Carers, particularly working Carers;
   - issues and concerns identified by staff who are Carers (see p38) that impact on Carers in general and;
   - the obligations of staff in relation to Carers as outlined in the NSW Carers (Recognition) Act 2010

   **Responsibility:**
   LHD Human Resources, Carers’ Program and CEWD
4. Review and promote available training options for LMs and Heads of Department.

Training should incorporate a Managers’ guide to negotiating flexible workplace arrangements for staff who are Carers and; information on Working Carers and their concerns and rights in relation to the NSW Carers (Recognition) Act 2010.

“New organisational strategies needed to be devised to ensure managers were appropriately trained and briefed to operationalise the policies. They also needed to be given freedom and training to decide what to do in individual cases based on assembling and then evaluating the business case for an employee’s request.”

Responsibility:
LHD Human Resources, Carers’ Program and CEWD

5. Develop Carer information resources for working Carers as a key priority that must occur as part of ongoing LHD HR processes at recruitment, orientation, initial 3 month review, annual performance review, 360 degree feedback.

Plain English and user-friendly information should be provided on the intranet about workplace entitlements. This includes policy and procedure regarding leave entitlements, flexible work practices, other government Carer entitlements and processes to access these entitlements.

Responsibility:
LHD HR and Carers Program in partnership with ISD

6. Champion working-hours flexibility for all staff and review existing organisational practices and barriers that inhibit flexibility while prioritising the core business of the organisation.

New and existing strategies that encourage workplace flexibility should be promoted such as early/late starts, long/ short days, split shifts, make-up time, time in lieu, school term-time working, job share, and work-from-home. These options support positive approaches to workplace diversity and will benefit Carers, the organisation and other employees who may be studying or juggling other demands and responsibilities.

“Shifts that would have suited me were not given. Other personnel were not one bit sympathetic”

“Had to use all available leave for my spouse’s funeral as leave without pay had to be prearranged – how bureaucratically absurd!”

Responsibility:
LHD Carers’ Program in partnership with HR, ISD and OHS Manager/Consultant
7. The Dementia, Carers and Disability Team, NSW Ministry of Health, should provide accurate information to NSW Health employees that promotes and clarifies the existing policy and entitlements around Personal Carers Leave through the process of the NSW Carers (Recognition) Act Implementation Plan.

This should reduce the confusion encountered by staff around PCL.

**Responsibility:**
Dementia, Carers and Disability Team, Inter-government and Funding Strategies and Integrated Care Branch

8. **Continue to monitor Carer baseline data by conducting a three yearly LHD survey.**

Use results of data and examples from overseas research to review and inform actions in the Conceptual Framework for Sustainable Support of staff who are Carers (1.4)

**Responsibility:**
LHD Carers’ Program in partnership with HR and ISD
8. Appendices

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8.3 The Infrastructure of Support for Carers..............................................52
8.1 Staff who are Carers Survey

ATTENTION - HEALTH EMPLOYEES WHO ARE CARERS
Please return original form only in the addressed envelope. Please do not fax, copy or scan this form as this may prevent compilation of data electronically.

For the majority of questions, you are asked to fill in the one response which best fits your views. Because your response will be "scanned" by a computer, please do this by filling in one circle only with a pen as in this example.

LIKE THIS:

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<tr>
<th>c. Are you allowed to participate in decision making?</th>
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<td>A little</td>
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<tr>
<td>A lot</td>
</tr>
<tr>
<td>A great deal</td>
</tr>
</tbody>
</table>

Please do not write in boxes.

If you make a mistake, please put a cross through the mistake and then fill in your preferred choice.

Q1. What is your age?

Q2. What is your gender?

Male
Female

The following 3 questions are optional

Q3a. Do you identify yourself as Aboriginal or Torres Strait Islander?
Yes
No

Q3b. Do you identify yourself as coming from a culturally and linguistically diverse background?

Q3c. What language is spoken most of the time in your home? – please select one

English
Vietnamese
Spanish
Greek
Arabic
Mandarin
Portuguese
Korean
Italian
Cantonese
Croatian
Other

Q4a. What is your work pattern? – please select one

Full time
Casual
Part time

8-16
17-24
25-32
33-38

Q4b. If you work part time, how many hours per week?
Q5. Please indicate who you provide the majority of your care to? – please select one
- Parents
- Neighbour/friend
- In-law/s
- Sibling
- Grandparent/s
- Children
- Husband/Wife/Partner
- Other

Q6. What are the main conditions, illness or disability of the person(s) you care for?
- Heart condition
- Arthritis
- Frail aged
- Dementia
- Stroke
- Cancer
- Diabetes
- Mental health
- Developmental disability
- Airways disease
- Brain injury
- Other-please specify

Q7. Where does the person(s) you care for live?
- In your home
- In another household alone
- In another household with others
- In a residential care facility
- Granny flat
- Other-please specify

Q8. How many hours a week do you provide care?
- 0-5
- 6-10
- 11-15
- 16-20
- More than 20

Q9. How many years have you been providing care?
- 0-2
- 3-5
- 6-10
- 11-20
- More than 20

Q10. How would you rate your general health?
- Excellent
- Generally good
- Not so good
- Poor

Q11a. Do you feel that providing care has had a negative impact on your own health and wellbeing?
- Yes
- No
- Unsure

Q11b. If yes, in what ways has it impacted?
- Physical injury
- General physical health
- Sleep patterns
- Emotional well-being
- Interpersonal relationships
- Other-please specify

Q12a. Do you need any support or hands on assistance with your caring role?
- Yes
- No

Q12b. If yes, from whom do you receive support/assistance?
- Friend/Relative/Spouse
- Community service
- Other-please specify
Q12c. If No, Why not?
- Manager without needing assistance
- Do not qualify for assistance
- No-one is willing or able to help
- Person you care for refuses help from others
- Still on waiting list for assistance
- Not sure where to obtain assistance

Q12d. Comments:

Q13. Do you feel that your caring role interferes or prevents you from having a social life, hobbies or other leisure activities?
- Always
- Most of the time
- Sometimes
- Never

Q14. Are the following sympathetic to your needs in your personal caring role?

Q14a. Employer
- Yes
- No
- They’re not aware of my caring role

Q14b. Manager
- Yes
- No
- They’re not aware of my caring role

Q14c. Other employees
- Yes
- No
- They’re not aware of my caring role

Q14d. Comments:

Q15. Does your caring role impact on the following:

Q15a. Hours and days you’re able to work
- Yes
- No
- Not applicable

Q15b. Taking extra shifts
- Yes
- No
- Not applicable

Q15c. Other employees
- Yes
- No
- Not applicable

Q15d. Ability to do shift work
- Yes
- No
- Not applicable

Q15e. Ability to work full-time
- Yes
- No
- Not applicable

Q15f. Sick/Annual/Long Service Leave days
- Yes
- No
- Not applicable

Q15g. Comments:

Page 3 of 4
Q16a. Have you had any difficulties in requesting Carer’s leave or other leave for reasons related to your caring role?
   Yes ☐   No ☐   Not applicable ☐

Q16b. If yes, what were the difficulties you experienced? – please choose one:
   Insufficient leave ☐   Unsure about process ☐   Unsure about entitlements ☐
   Leave not approved by manager ☐   Other Please specify ☐

Q16c. Comments:

Q17a. Are you aware of the Carer Payment and Carer Allowance from Centrelink?
   Yes ☐   No ☐   Unsure ☐

Q17b. If yes, are you eligible?
   Yes ☐   Yes and already receiving benefits ☐   No ☐

Q18. What education and training topics do you think would be useful for carers to know more about?

Q19. As a carer, what education and training topics would you think it would be useful for health professionals to know more about?

Q20. Do you have any further comments, recommendations or practical ideas that would assist us to support you better in both your caring role and in the workplace as a Carer?

Thank you for your time and assistance in answering this questionnaire. If you would like any more information please see the separate page with this survey.
8.2 Example of Workplace Caregiving Assistance Programs

Data extracted from Family Caregiver Alliance

1. Employee benefits in the form of supplemental dependent care coverage to reimburse costs for in-home or adult day care or long-term care insurance
2. Human resources or employee assistance program staff to provide assistance
3. Caregiver support groups, in-house or coordinated with outside support groups
4. Flexible work hours, family illness days, leave time
5. Family and Medical Leave Act guidelines (used by smaller firms with fewer than 50 employees)
6. Supporting worksite activities such as caregiver fairs, seminars, hotlines and published materials.
### 8.3 The Infrastructure of Support for Carers

From *Carers Employment and Services: time for a new social contract* Fig 6.19 p 35

<table>
<thead>
<tr>
<th>Local Providers of Social Care</th>
<th>Local Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TO ACCESS THESE SERVICES CARERS NEED</strong></td>
<td><strong>TO ACCESS THESE SERVICES CARERS NEED</strong></td>
</tr>
<tr>
<td>- Adequately resourced, responsive local social care infrastructure</td>
<td>- Adequately resourced, responsive local health care infrastructure</td>
</tr>
<tr>
<td>- Access to information, advocacy, advice and support</td>
<td>- Professionals aware of carers' needs</td>
</tr>
<tr>
<td>- Capacity to articulate needs and negotiate with providers</td>
<td>- Professional support and education</td>
</tr>
<tr>
<td>- Separate assessment of need and eligibility</td>
<td>- Clear pathways to accessing services</td>
</tr>
<tr>
<td>Services to users</td>
<td>- GP services</td>
</tr>
<tr>
<td>- Information and advocacy</td>
<td>- Health Visitor/mtor/iliary Health</td>
</tr>
<tr>
<td>- Home care</td>
<td></td>
</tr>
<tr>
<td>- Day care</td>
<td></td>
</tr>
<tr>
<td>- Social support</td>
<td></td>
</tr>
<tr>
<td>- Family support</td>
<td></td>
</tr>
<tr>
<td>- Evidence based practice and intervention</td>
<td></td>
</tr>
<tr>
<td>- Empowerment, rights, and empowerment</td>
<td></td>
</tr>
<tr>
<td>- Right outside the housing market</td>
<td></td>
</tr>
<tr>
<td>- Right to control</td>
<td></td>
</tr>
<tr>
<td>- Right to control</td>
<td></td>
</tr>
<tr>
<td>- Right to control</td>
<td></td>
</tr>
<tr>
<td>Information and service</td>
<td>- Other Local Infrastructure</td>
</tr>
<tr>
<td>- Employment rights, policies</td>
<td>- High quality local infrastructure for everyday life</td>
</tr>
<tr>
<td>- Support networks</td>
<td>- Carers awareness, local service providers</td>
</tr>
</tbody>
</table>

*Fig 6.19: The Infrastructure of Support for Carers*
9. References


ABS *A Profile of Carers in Australia* 444 8.0 2008 p2

Linda Cox Curry, Charles Walker and Mildred O Hogstel *Educational Needs of Employed Family Caregivers of Older Adults: Evaluation of a Workplace Project* Geriatric Nursing Vol 27 No.3


Mary Gilhooly and Calum Redpath, *Private Sector Policies for Care Giving Employees* Ageing and Society 17, 1997

Peg Krach and Jo A. Brooks, *Identifying the Responsibilities & Needs of Working Adults Who are Primary Caregivers* J of Gerontological Nursing USA October 1995

S. Payne and L. Doyle *Older Women, Work and Health* UK School for Policy Studies, University of Bristol UK 2010


Sue Yeandle; Cinnamon Bennett, Lisa Buchner, Gary Fry and Christopher Price *Managing Caring and Employment* Report No. 2 Carers, Employment and Services Report Series; Carers UK and University of Leeds 2007


## 10. Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>AHS</td>
<td>Area Health Service</td>
</tr>
<tr>
<td>AOE</td>
<td>At Own Expense</td>
</tr>
<tr>
<td>AL</td>
<td>Annual Leave</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>COB</td>
<td>Country of Birth</td>
</tr>
<tr>
<td>CRGH</td>
<td>Concord Repatriation and General Hospital</td>
</tr>
<tr>
<td>FACS</td>
<td>Family and Community Services Leave</td>
</tr>
<tr>
<td>HGD</td>
<td>Higher Grade Duties</td>
</tr>
<tr>
<td>LWOP</td>
<td>Leave without Pay</td>
</tr>
<tr>
<td>LOTE</td>
<td>Language(s) Other Than English</td>
</tr>
<tr>
<td>NR</td>
<td>No Response</td>
</tr>
<tr>
<td>OL</td>
<td>On Line</td>
</tr>
<tr>
<td>PCL</td>
<td>Personal Carers Leave</td>
</tr>
<tr>
<td>SL</td>
<td>Sick Leave</td>
</tr>
<tr>
<td>SLHD</td>
<td>Sydney Local Health District</td>
</tr>
<tr>
<td>SSWAHS</td>
<td>Sydney South West Area Health Service</td>
</tr>
<tr>
<td>Stat dec</td>
<td>Statutory Declaration</td>
</tr>
<tr>
<td>SWSLHD</td>
<td>South Western Sydney Local Health District</td>
</tr>
<tr>
<td>TCH</td>
<td>The Canterbury Hospital</td>
</tr>
<tr>
<td>LOTE</td>
<td>Languages Other Than English</td>
</tr>
<tr>
<td>LM</td>
<td>Line Manager</td>
</tr>
<tr>
<td>DH</td>
<td>Departmental Heads</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
</tbody>
</table>
11. Endnotes

3 Antidiscrimination Legislation ADB Fact Sheet page 1, paragraph 1
4 Fair Work Act 2009 Section 65 Division 4(1)
5 ABS A Profile of Carers in Australia 2008 444 8.0 p2
6 NSW Carers Recognition Act (2010)
8 SWSLHD Workforce Profile May 2012
This report is the sixth in a series commissioned by Action for Carers and Employment led by Carers UK and produced by the University of Leeds. Another report in this series, Managing Caring and Employment (Report No. 2) is also cited. Culturally and Linguistically Diverse (CALD) Carer Groups are referred to as Ethnic Minority Carer Groups.
12 NSW DPC 2010/11 Workforce Profile (v2011.09.14);
13 SSWAHS Workforce Profile October 2009
14 In relation to Access to Carer Entitlements, Carer Payment is made by the Commonwealth Government to individuals who are unable to support themselves through substantial paid employment. This is because they are providing daily care to a person with a severe disability, medical condition or who is frail aged. Similarly, Carer Allowance is paid to Carers providing the same care and attention to someone with a severe disability, medical condition or who is frail aged but is not means tested and can be paid in addition to wages or other income support payments.
16 Mary Gilhooly and Calum Redpath, Private Sector Policies for Care Giving Employees— Ageing and Society 17, 1997 pp413 - 414
17 Peg Krach and Jo A. Brooks, Identifying the Responsibilities & Needs of Working Adults who are Primary Caregivers in J of Gerontological Nursing p41 USA October 1995 citing S Sullivan and B Gilmore Employers Begin to Accept Elder Care as a Business Issue Personnel, 68 p3 - 4
18 Sue Yeandle, Cinnamon Bennett, Lisa Buckner, Gary Fry, Christopher Price Managing Caring and Employment, Carers UK and University of Leeds Report No. 2 2007 p13
19 A Profile of Carers in Australia P5
21 Reported in Managing Caring and Employment The survey was commissioned by Carers UK, lead partner in the “Action for Carers and Employment” partnership, and was carried out by Leeds University in 2006 – 2007. The findings reported were based on 1,909 responses to a national survey targeting carers of working age.
22 Managing Caring and Employment p30
26 Op. cit Managing Caring and Employment p 15
27 Who Cares Wins p10
28 Carers Employment and Services p12
29 Op. cit Carers Employment and Services p7
31 Managing Caring and Employment p10
Linda Cox Curry, Charles Walker and Mildred O Hogstel *Educational Needs of Employed Family Caregivers of Older Adults: Evaluation of a Workplace Project* in Geriatric Nursing Vol 27 No.3 p168 Table 2 extracted from Family Care Givergiver Alliance [www.caregiver.org/caregiver](http://www.caregiver.org/caregiver) 2005


Managing Caring and Employment P11

Anne Catrine Eldh and Eva Carlsson *Seeking A Balance Between Employment and the Care of an Ageing Parent* in Scandinavian Journal of Social Sciences Nordic College of Caring Science 2010 p287


Managing Caring and Employment Executive Summary p iv - v

*Who Cares Wins* p39

Op. cit. see endnote xxix *Educational Needs of Employed Family Caregivers of Older Adults: Evaluation of a Workplace Project (LC Curry)*


Mark McCarthy *Supporting Employees with Carer Responsibilities*, A paper presented at the Carers NSW Biennial Conference Railcorp NSW Transport 2011


Op. cit. see endnote 17 *Working Adults who are Primary Caregivers* p47

Op. cit. see endnote 32 *Educational Needs of Employed Family Caregivers of Older Adults* pp166 - 173

An Unpublished report on *Carer Complaints in SSWAHS*. This unpublished report detailed findings from a search of complaints made by Carers to SSWAHS in 2010. The report identified areas of improvement for the attention of senior AHS staff in relation to providing services to patients and their Carers. This report noted lack of awareness by some staff in providing care to elderly people and people with disabilities.

*Who Cares Wins* p35 - 37

Op cit. See endnote 2 *Carers, Employment and Services: time for a new social contract?* Executive Summary p iv

Op. cit. see endnote 15 *Working People Who also Care for the Elderly*

*Who Cares Wins* p23

*Who Cares Wins* p26 & 29

S. Payne & L. Doyle *Older Women, Work and Health* School for Policy Studies, University of Bristol UK in Occupational Medicine 2010; 60:172 -177

Op. cit. see endnote 43*Supporting Employees with Carer Responsibilities* M McCarthy P6

Who Cares Wins p30

Who Cares Wins p13-33

Who Cares Wins p21

Op. cit. see endnote 43*Supporting Employees with Carer Responsibilities* M McCarthy


Yeandle et al in *Who Cares Wins* p6 citing S Dex 2003: 25 *Families and Work in the Twenty First Century*

Joseph Rountree Foundation York UK